King County Asthma Forum
Allies Against Asthma

PLANNING YEAR EVALUATION REPORT

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EXECUTIVE SUMMARY

Introduction

King County Allies Against Asthma (AAA) is a project of the King County Asthma Forum (KCAF) designed to improve the health of low-income children with asthma located in Central and South Seattle and Southwest King County. King County AAA is one of seven sites from around the United States that received funding by a four-year grant from The Robert Wood Johnson Foundation (RWJ) Allies Against Asthma project. The national RWJ AAA project is intended to develop models that improve access to and the quality of clinical care, reduce and prevent asthma symptoms and environmental triggers, foster patient and community education, and strengthen community-based asthma coalitions.

This report covers the planning phase of AAA, which encompasses the calendar year January 1, 2001 to December 31, 2001. The planning year evaluation used a qualitative case study design drawing on a variety of data sources including key informant interviews with AAA stakeholders, closed-ended surveys of KCAF members, program records, grant proposals, meeting minutes, coalition-wide e-mail messages, progress reports, observation, and other program records.

Program Description

The King County Asthma Forum (KCAF) is a coalition of schools, public health and housing agencies, academic institutions, hospital systems, health plans, community clinics and other health providers, and community organizations created in 1998 through a joint effort of the American Lung Association of Washington and Public Health - Seattle & King County. The mission of the KCAF is to bring together individuals and agencies to establish an on-going asthma network to communicate about, collaborate on, and coordinate projects that improve and support asthma prevention, diagnosis, and management in King County.

KCAF was awarded $149,811 by RWJ for an initial planning year to develop a strategy for addressing childhood asthma in these communities. The goals for KCAF during the AAA planning year can be grouped into two broad areas: (1) to complete a community assessment process and develop a comprehensive three-year implementation plan to be approved by the national Allies Against Asthma program; and (2) to take steps to strengthen KCAF as a coalition, including having functioning committees, increasing community participation, establishing a community presence and reputation, and increasing cultural competence among KCAF members.

Evaluation Findings

Evaluation findings are organized by the two overarching goals of the AAA planning year: to carry out a community-driven process to develop a three-year intervention plan and to strengthen KCAF as a coalition.

Goal 1: Developing an Allies Against Asthma Intervention Plan

As part of the process of developing an intervention plan, the KCAF conducted a community needs and asset assessment, developed priorities, and formulated a detailed intervention plan. Assessment activities included two community summits, ten focus groups, and thirteen key

informant interviews. Additionally, the Communications Action Team (a committee of the coalition) mapped community assets within the larger target area. Data were also examined from a variety of sources including prevalence data from the Behavioral Risk Factor Surveillance System (BRFSS), hospital discharge data, and asthma treatment information from clinical records.

Several major themes emerged from the community assessment process and KCAF planning meetings. The first and perhaps most significant key theme that emerged was the need for improved self-management and control of triggers in the home. A second was for improved clinical care. A third was for increased understanding and education for all people and at all places where the child spends time: home, childcare, recreation, schools, and throughout the community. A fourth was increased coordination and sharing of consistent information across sites.

The intervention plan that was adopted incorporates these priorities into multiple strategies at the levels of the home (which includes child and family), clinic, school, childcare site, community, and institution (including policy makers). The strategies include improving asthma self-management, enhancing the quality of the environment in a variety of settings (e.g., home, school, childcare facilities), improving clinical management, increasing community awareness and promoting effective asthma control policies.

The AAA planning process was evaluated along several dimensions, including stakeholder opportunities for input, organization, inclusiveness and results. Most informants were satisfied with the way the process was organized and carried out and also with the Community Action Plan that was produced. Stakeholders were particularly satisfied with the effort to provide opportunities for input; for example as one respondent said (Note: throughout the report, text in smaller font and italics are quotes from the key informant interviews):

> *The grassroots input was excellent and there was a lot of opportunity for input. They also tried to organize and publicize the meetings to give the community a chance to participate. It was a very pluralistic process.*

However, there was also agreement that despite strong efforts to include community residents and community-based organizations in the planning process, these efforts had not generally been successful. As one key informant said:

> *It was difficult getting community people involved in the process. Moving meetings out into the community was a good change. I think the meetings were very scary for community members, locations were tough too, when they were not being moved around.*

<u>Goal 2: Strengthening KCAF as a Coalition</u>

KCAF carried out a number of activities to strengthen itself as a coalition including formalizing the governance structure, creating standing committees, doing outreach to increase community participation and promoting cultural competency among members. Data from key informant interviews and a closed-ended coalition member survey were used to assess the effectiveness of these coalition-building efforts.

The coalition member survey results showed that satisfaction with communication, trust and leadership of the coalition were relatively high (rankings of 3.7-3.8 on a 1-5 scale), while items related to community involvement - diversity of membership, community presence - were rated lower (3.0-3.1).

Key informants listed commitment of the members as a main coalition strength including how much they care about their work, each other, and their willingness to set aside personal and organizational goals for the broader good; for example:

> *I am impressed by the energy and passion/enthusiasm members have. They are determined and are willing to put in time.*

Responses to the question about KCAF challenges focused primarily on the recurring theme of a lack of community representation:

> *At the steering committee we are not as rooted in community-based organizations as we would like to be. But sometimes this is an elusive and idealistic goal, but we always want to keep it on the table and keep striving for it.*

An additional challenge during the planning period for the coalition was a lack of adequate staff resources:

> *The whole effort has been primarily based on good faith efforts of volunteers. We have had very little staffing to date.*

A final challenge that emerged was around governance and organizational structure. Common respondent themes focused on lack of clarity and loose boundaries between Allies and the Forum, difficulties integrating various asthma projects associated with the Forum, and a lack of clarity between the committees and projects:

> *This (integration of various projects) is a very critical area and is unclear. No one reality seems to exist that we can all agree upon. The coalition must do something about this, so we are all able to see the same reality.*

Summary/Lessons Learned

King County Allies Against Asthma achieved all of the major objectives it set for itself during the planning year including carrying out an extensive needs assessment process, setting priorities, and developing an intervention plan. The King County Asthma Forum was also largely successful in achieving its major objectives, including strengthening itself as a coalition and developing functioning committees. The major challenge identified for both AAA and KCAF was a lack of community participation in either the KCAF coalition or the AAA planning process.

Key lessons learned during the planning year included:

- Governance structures evolve over time. Coalition development and creation of an effective governance structure is an evolutionary process; the governance structure will need periodic assessment to ensure it continues to optimally support the work;
- Membership recruitment is challenging during a planning process. Expecting active growth of coalition membership during the planning year is unrealistic.

- It is difficult to organize interventions in large, diverse neighborhoods. The geographic diversity and breadth of the target communities inhibits the ability to deeply penetrate a neighborhood with organizational efforts and may require designing several innovative methods for sharing and disseminating information;
- Multiple, creative recruitment strategies are required. Participation and membership needs to be broadly defined with multiple points of entry into activities.
- Effective participatory community-based planning takes time. One year is not an adequate amount of time to conduct a community-based planning process with the purpose of developing a health improvement project. On the other hand, having an intensive process with a defined timeline required stakeholders to work closely together, resulting in a durable relationship built on trust and mutual respect. The "social capital" has become a valuable asset for the KCAF.
- Paid staff, a core of dedicated leaders to help keep the process moving, and an institutional base of support (as provided by Public Health – Seattle King County) are all critical for success. Adequate staffing is critical in the early phases and beyond to facilitate penetration into a community while simultaneously meeting the complex demands of the funding agency and the local stakeholders.

KCAF is incorporating many of these lessons as it moves forward into the implementation phase of the Allies Against Asthma program. For example, the intervention activities are using a variety of outreach strategies to recruit participants.

I. Introduction

King County Allies Against Asthma (AAA) is a project of the King County Asthma Forum (KCAF) designed to improve the health of low-income children with asthma located in Central and South Seattle and Southwest King County. King County AAA is one of seven sites from around the United States that received funded by a four-year grant from The Robert Wood Johnson Foundation (RWJ) Allies Against Asthma project (see **Appendix A** for a list of the grantees). The national RWJ AAA project is intended to develop models that improve access to and the quality of clinical care, reduce asthma symptoms and foster patient and community education. In addition, a portion of the grant is directed at developing a community-based coalition and understanding the processes involved in coalition building and methods to incorporate community involvement.

This report covers the planning phase of AAA, which encompasses the calendar year January 1, 2001 to December 31, 2001. The report describes the AAA program, summarizes planning year goals, and assesses how well those goals were achieved. It also documents and assesses objectives around coalition development and the extent to which they were achieved. The final section highlights lessons learned that might apply to the implementation phase of the project and summarizes how some of the key challenges identified during the Planning year have since been addressed.

The planning year evaluation used a qualitative case study design drawing on a variety of data sources, including key informant interviews with AAA stakeholders, closed-ended surveys of KCAF members, program records, grant proposals, meeting minutes, coalition-wide e-mail messages, progress reports, and other program records.

II. Program Description

A. National Allies Against Asthma

Asthma is a chronic inflammatory disease of the airways, affecting more than 14.9 million Americans, including an estimated 5 million children. Rates in children have increased by 75% since 1985. To help combat the rising tide of asthma among children, in 2001 the Robert Wood Johnson Foundation awarded grants to eight communities to develop models that improve access to and the quality of clinical care, reduce asthma symptoms, and foster patient and community education. The grants are being made under the Foundation's *Allies Against Asthma* program, which is administered by the University of Michigan School of Public Health. The National Program Office at the University of Michigan provides overall direction and technical assistance for the initiative.

Through the Allies Against Asthma initiative, seven community coalitions were awarded grants to support the coalition, its targeted activities and evaluation. Community coalitions are based in Hampton Roads, VA; Long Beach, CA; Milwaukee, WI; Philadelphia, PA; Seattle/King County, WA; Washington, DC; and San Juan, Puerto Rico. Each site was awarded one-year planning

grants of about $150,000 and three-year implementation grants of up to $1.2 million. The coalitions – which include clinics, hospitals, public health agencies, schools, parents, child care providers, housing and environmental organizations, researchers, and public health agencies – will combine clinical and public health approaches to control asthma in their communities (see **Appendix A** for list of partnerships).

The primary aims of the Allies Against Asthma program are to:

- Enhance the quality of life of children with asthma;
- Reduce hospital admissions, emergency room visits, and number of missed school days by children with asthma; and
- Develop a sustainable strategy for asthma management within communities.

If these partnerships succeed, the Foundation anticipates replicating the Allies Against Asthma approach for mobilizing community resources against other chronic health conditions.

B. King County Allies Against Asthma

King County Allies Against Asthma was created when the King County Asthma Forum (KCAF) received funding from The Robert Wood Johnson Foundation Allies Against Asthma project to improve the health of low-income children with asthma located in Central and South Seattle and Southwest King County. KCAF was awarded $149,811 by RWJ for an initial planning year to develop a strategy for addressing childhood asthma in these communities. The goals for AAA during the planning year were to:

- Complete an asset map and needs assessment,
- Define AAA's priorities, and
- Develop an intervention plan.

The KCAF also established objectives for itself as a coalition during the planning year:

- Attain the characteristics of a successful coalition,
- Have functioning committees,
- Increase community participation,
- Establish community presence and reputation, and
- Increase cultural competence among KCAF members.

At the end of the planning year, KCAF was awarded a three-year implementation grant of $1.2 million from RWJ to serve children with asthma in the target area. These funds will be augmented with Medicaid and Public Health-Seattle & King County matching funds and in-kind contributions from other coalition partners. The planned interventions are described in more detail below under Section III, Evaluation Findings.

<u>Allies Against Asthma Target Population</u>

The AAA target population is children age 2-17 with persistent asthma that lives in low-income households (<250% poverty) in Central and South Seattle and Southwest King County. It was

estimated that the current asthma prevalence rate among children in the target population is at least 12%, or 4,800 individuals.

This area was selected because of its high rate of asthma hospitalization and significant cultural and socioeconomic barriers to asthma management. The asthma hospitalization rate per 100,000 for children in the target area (averaged over 1994-1998) was 418.9, compared to 213.2 for King County, and 334.1 for Seattle. Between 1988 and 1995, the hospitalization rate in the target area increased 62%. The rate has declined in recent years but remains significantly higher than the 1988 rate. The prevalence of children with asthma among the patients served by many of the clinics in the target area is higher than the state average.

In 2000, the King County population was 1,737,034, including 390,646 children under age 18. The AAA geographic catchment area includes Central and Southeast Seattle, Westwood, White Center/Skyway, and part of Highline/Burien and Renton. Several clinics will be participating in the Allies interventions, at three different levels of grant funding. Those clinics that are being fully funded to carry out a set of comprehensive interventions are Puget Sound Neighborhood Health Clinic (PSNHC) Rainier Park, Rainier Beach, and Seamar, Columbia, and Highline Roxbury clinics. Those receiving funding for a subset of interventions are PSNHC High Point and Northgate clinics. Finally, Eastside clinic is participating voluntarily in some of the interventions.

Approximately 40,000 children under age 18 live in the catchment area. Because the catchment area is large, two smaller high intensity areas (Rainier Valley and Highline/Burien) within the area were selected for more intensive intervention in order to maximize the potential for favorably influencing asthma morbidity.

Considerations in defining these high intensity intervention areas included: geographic proximity to the zip code areas with high hospitalization rates, the presence of strong community assets (interested partner schools, primary care sites, and CBO's), concentration of low-income and minority populations, and desire and support for participation in defining these areas. AAA is emphasizing working with low-income African American, Vietnamese and Latino ethnic groups within the geographic areas of focus because of higher asthma morbidity among these populations.

C. King County Asthma Forum

The King County Asthma Forum (KCAF) is a coalition of schools, public health and housing agencies, academic institutions, hospital systems, community clinics and other health providers, residents, and community organizations created in 1998 through a joint effort of the American Lung Association of Washington and Public Health - Seattle & King County. The KCAF brings together individuals and agencies to establish an on-going asthma network to communicate about, collaborate on, and coordinate projects that improve and support asthma prevention, diagnosis, and management in King County. Specific KCAF objectives include:

- Establish an on-going communication network within King County,

- Identify individuals and agencies that may want to participate in the forum,
- Identify gaps in existing services and activities in King County,
- Identify opportunities for coordination and collaboration across projects and agencies,
- Increase awareness of asthma, including prevention, diagnosis and management, and
- Develop activities to improve control of asthma in King County.

The KCAF vision is a future in which every child with asthma in King County will lead a full and active life, unimpeded by physical and psychological limitations related to asthma. The KCAF sees an asthma control system that integrates efforts of children with asthma, their families, their social networks, their health providers, their schools and their communities into a coherent child and family-centered approach. The KCAF sees a system that addresses the concerns and values of low-income and minority families in a culturally competent manner.

Membership and Governance

The King County Asthma Forum is open to all organizations and individuals concerned with asthma in King County. Multiple individuals from a single organization can be members, preferably each representing a different unit within his/her organization. Members may represent themselves or a specific organization. To retain voting rights, members need to attend at least two of the four KCAF meetings per year. The KCAF general membership meets quarterly to:

- Facilitate communication and networking among persons and organizations who have an interest in asthma;
- Share experiences, problems and successes;
- Transmit current asthma-related knowledge;
- Provide general oversight of all KCAF projects (defined below);
- Approve new KCAF projects;
- Select at-large Steering Committee members;
- Select Forum Chair and Co-Chair; and
- Review and approve Steering Committee decisions.

The general membership elects a Chair and Co-Chair to serve one-year terms. The roles of the Chair are to: facilitate Steering Committee and general membership meetings, represent the KCAF or delegate this task to another member, and serve on the Steering Committee. The membership of the Steering Committee consists of:

- Forum Chair and Co-Chair,
- Standing Committee Chairs,
- Project Directors or Principle Investigators (PI) of ongoing Forum projects, and
- Four at-large members.

The at-large members of the Steering Committee serve three-year staggered terms and are elected by the general membership at the fall quarterly meeting in the same manner as the Chair and Co-Chair. The standing committee chairs are selected by the memberships of each committee for one-year terms. The Project Directors and Principal Investigators of Forum projects serve as long as the projects continue.

The Steering Committee meets monthly to provide vision and guidance to the KCAF, provide oversight to all Forum projects at the operational level, and to make interim decisions for the KCAF between quarterly meetings. These decisions are reviewed at the next quarterly meeting and can be re-opened for discussion, amendment or rejection at the request of a member attending the meeting.

KCAF also has several standing committees to carry out the work of the Forum, including: Schools, Clinical, Governance, Environmental Outreach, and Education, and Parents and Community Membership in the standing committees is open to anyone who is interested.

III. Evaluation Findings

The evaluation findings are grouped by the eight planning year goal areas listed below (three for Allies Against Asthma Project and five for KCAF-). Within each goal area, progress is summarized and an attempt is made to assess the quality and/or success of the effort. For the Allies against Asthma objectives, this assessment is made collectively for all three objectives since all three relate to intervention planning (Section 4 below under AAA).

Allies Against Asthma objectives:

1. Complete asset map and needs assessment,
2. Define AAA's priorities, and
3. Develop an intervention plan

King County Asthma Forum objectives:

1. Attain the characteristics of a successful coalition,
2. Have functioning subcommittees,
3. Increase community participation,
4. Establish community presence and reputation, and
5. Increase cultural competence among KCAF members.

These objectives are described in more detail in the sections that follow, along with a summary of progress toward the objectives made during the planning year. As noted in the Introduction, assessment of progress draws on a variety of data sources, including key informant interviews with AAA stakeholders, closed-ended surveys of KCAF members, program records, grant proposals, meeting minutes, progress reports and other program records. Key informant interviews were conducted with members of KCAF in spring, 2001 (N=16) and again in spring of 2002 (N=16). The survey of coalition members was conducted in the summer, 2001 (N=35).

A. King County Allies Against Asthma

1. Complete asset map and needs assessment

An important AAA objective during the planning year was to assess the assets and needs of the target communities. This assessment was guided by the recognition of the interplay among the child and family, the social network and the community.

The KCAF assessed needs and assets by conducting two community summits, ten focus groups and thirteen key informant interviews. Additionally, the Communications Action Team mapped community assets within the larger target area. Data were also examined from a variety of sources, including prevalence data from the Behavioral Risk Factor Surveillance System (BRFSS), hospital discharge data, and asthma treatment information from clinical records. The asset mapping/needs assessment process is described in this section.

Community Asthma Summits

Two Community Asthma Summits were held in May 2001. The first summit on May 19 was located in Tukwila, a city of South King County. The second summit, in Seattle, was on May 20. Each had an educational presentation followed by three breakout sessions to discuss asthma and seek community insight into what would benefit children with asthma. The three breakout sessions were in English, Vietnamese, and Spanish. Observers took notes and taped the discussion. Approximately 30 families attended both summits.

Participants wanted more education for school personnel, parents, relatives, and childcare providers. Suggested sites for providing outreach and education included the workplace, malls, libraries, stores (e.g. pet stores), and parks. Other needs included linguistically and culturally appropriate educational materials and a childcare site for ill children with asthma. Questions asked by the participants about asthma were recorded to assist in the development of future materials and presentations

Focus Groups

Ten focus groups of key stakeholders were conducted at various locations in King County. The focus groups included three parent groups (African American, Vietnamese and Latino), two youth groups (middle school and high school), and five provider groups (child care providers, school nurses, public health nurses, outreach workers and medical providers). A facilitator conducted eight English-speaking focus groups and trained two bilingual native speakers to conduct non-English-speaking (Vietnamese and Spanish) focus groups.

Focus groups lasted 90 minutes except for the school groups, which were 60 minutes. Each focus group reviewed previous groups' lists of desired interventions, commented on them, and then added their own ideas. Focus group sessions had a note-taker, were audio taped, and the English language tapes were transcribed. The non-English tapes were used by the note-takers to augment their notes. Two coalition members coded transcribed tapes and the Vietnamese and Spanish translated notes. Analysis was done by intensive review of the coded transcripts, notes and audio-tapes to identify themes important to these groups.

The groups yielded many suggestions for interventions; those that emerged as the highest priorities were:

- Pediatric asthma control activities: expand Healthy Homes/environmental home assessment, engage pharmacists to give specific information on inhaled steroids, and develop standardized care and documentation systems.
- Services: provide child care for ill children with asthma, tutors for children with asthma, visual asthma messages (video, poster), trips and activities for kids with asthma, (Wild Waves, ice-skating, etc.), a play to teach about asthma, roving asthma educators for parents and children, and implement a toll-free asthma information number for the public.
- Provider support: ensure continuing education credit for child care providers.

Non-Member Key Informant Interviews

AAA investigators interviewed 13 key informants who were not members of the KCAF at the time of the interview with the purpose of including more stakeholders in the process. The informants represented the diversity of our target populations (five African Americans, four Latinos, two Vietnamese, and two Caucasian), and included a mix of stakeholders, such as outreach and community health workers (social work, medical, family support), health care professionals (pharmacy, medicine, mental health), educators, recreation staff, members of faith communities, a child, and CBO executives. Two of the interviewed organizations have since joined the KCAF, and one joined the Steering Committee. Three are planning to involve KCAF in outreach activities.

The key informants identified additional needs and assets. A majority cited lack of education as a key factor limiting the lives of children with asthma. They desire improved, culturally appropriate and targeted educational programming and information. Training was requested for childcare and recreation staff, coaches, families, neighborhoods, and the peers of affected children. The Vietnamese respondents suggested radio and newspapers as the optimal vehicles. The Latino respondents cited community events, educational sessions after church, and bus ads. The African American respondents suggested puppet and theater productions, videos, billboards, bus ads, and barbershop/hair salon outreach.

The coach, CBO staff, childcare center staff, and pharmacist all desired more connection with health care providers. They suggested that the providers' record after school activities and conversely that sports and childcare forms have more accurate medical information. Seven respondents felt that home environmental assessment is important. All were interested in obtaining educational materials distributed by the KCAF and five expressed interest in participating in outreach efforts and interventions with the KCAF.

Secondary and Other Data

- Home environmental exposures to asthma triggers - Data from the Healthy Homes-I project demonstrated that exposure to indoor asthma triggers is common among low-income households, especially mold, tobacco smoke and dust mites. Most homes had moisture problems and/or inadequate ventilation and nearly all had carpeted floors.

Nearly all lacked allergy control bedding encasements and effective, low-emission vacuums.

- Prevalence - In 2000, the prevalence of active asthma in King County among children under age 18 was 5.6%. Averaged over 1999-2000, the active asthma prevalence among age group 0-4, 5-12, and 13-17 was 3.5%, 6.9%, and 6.0% respectively. The rate for African Americans was substantially higher than the rates for other racial/ethnic groups. Children from lower income households also had a higher rate.
- Hospitalization - The asthma hospitalization rates in Central and Southeast Seattle were substantially higher than the rest of King County. The rates in White Center/Skyway, West Seattle, and Highline/Burien were also significantly higher than the King County average rate.
- Chart review - 129 randomly selected medical records were abstracted of children age 4-17 who had two or more clinic visits for asthma during the past year from safety net health providers in the catchment area, including PHSKC, Puget Sound Neighborhood Health Clinics, and Community Health Centers of King County. The results showed that few had documented allergy tests, spirometry, or education concerning indoor asthma triggers. Less than one third of the patients had a documented asthma action plan and inhaled steroids were underutilized.

In summary, the AAA needs and asset assessment process use a variety of methods to get information from families of children with asthma and from community-based organizations. Perceived and actual needs from a culturally diverse sample frame were identified, documented, and then incorporated into the development of AAA interventions. The methods used were rigorous and the sample sizes adequate to get a broad cross-section of opinions.

2. Define AAA's priorities

The priorities of AAA that are embodied in the three-year intervention plan emerged from a combination of the community needs assessment process and KCAF meetings including planning retreats, general membership meetings, and Steering Committee and standing committee meetings. This section examines both the overall priorities of KCAF/AAA and the specific priorities from the community needs assessment process that guided intervention development.

Broad Priorities/AAA Mission

The most recent vision statement for AAA is: *"The King County Asthma Forum, through Allies Against Asthma, brings diverse communities together to decrease the burden of asthma on families. The Allies Against Asthma project gives communities a way to focus on the needs of our most vulnerable children with asthma."* Fourteen forum members were interviewed to get their perspective on how well KCAF was realizing this vision. The interviews included questions about AAA goals and priorities to assess how KCAF members interpreted this fairly broad vision. Priorities mentioned by respondents fell into three broad areas: coalition development, intervention development, and systems coordination.

One priority area was to further develop KCAF as a coalition, particularly broadening its membership:

Develop a coalition – infuse more community participation and optimize its functioning. Increase the number and variety of people involved.

Build a base in the target community so that families are involved in the process of improving asthma care services.

First priority: Coalition building – develop, grow and strengthen the coalition so that it can be sustained.

Develop the coalition and get the community involved in the work.

A second priority area was intervention development:

Develop an intervention that cuts across many different areas, with children at the center. It will incorporate schools, medical care, homes, and childcare.

Get schools involved in improving the management of asthma in the school setting, and improve clinical care of kids with asthma.

Patient and family outreach and education, Work with providers and clinics to ensure asthma care is state of the art, Support health care providers, Environmental assessments, and School assistance – helping provide care for kids while they are at school.

Design a community-based intervention to improve asthma care and therefore outcomes to kids in targeted areas within KC that effectively addresses the needs of these populations.

Support and promote best practices. Improve asthma management at the family and community level by informing families and people who care for kids with asthma outside of the clinical setting. Decrease morbidity with regards to asthma and all components such as sick time, quality of life, health care use, and ED use.

A third shared priority area was the establishment of a more coordinated system of care for children with asthma.

To coordinate both the services of the forum and to make the services offered by others better coordinated with one another.

Have a comprehensive system in place in KC for people who have asthma that links various aspects of care for patients such as within the clinic setting, the environment, and various support services.

Develop coordinated care to improve asthma management, which shows up in reduced hospitalization rates. Help the community better understand the care required to manage asthma and to improve self-management. The key really is "coordinated care".

These three overall priority areas are all consistent with the goals of the National AAA program.

Priorities from Needs Assessment Process

Several major themes emerged from the community assessment process. The first was the need for improved self-management and control of triggers in the home. A second was for improved clinical care. A third was increased understanding and education for all people and at all places where the child spends time: home, childcare, recreation, schools, and throughout the

community. A fourth was increased coordination and sharing of information across sites. The following is a brief description of the areas of improvement selected using the community assessment process as a guide:

- Improving asthma self-management - Assessment data indicated low documented rates of asthma management plans and self-monitoring. Children and parents cited an interest in more education for self-management.
- Improving control of home environmental triggers - Most respondents (both families and providers) cited reduction of home environmental triggers as an important area to address. Data from the chart review and from Healthy Homes I[1] suggest that in the clinical setting, most families do not receive education about home environmental triggers.
- Improving clinical management - Providers and all other stakeholders recommended quality improvement efforts in clinical management and a registry to improve implementation of asthma management guidelines.
- Improving school management - Schools continue to struggle with questions of medication distribution, adequate nurse staffing and environmental issues. Additionally, most focus groups commented on the need for school staff to have up-to-date information about their children with asthma and education on a variety of topics such as asthma symptoms, exercise among children with asthma, management of asthma exacerbations and access to medications.
- Improving childcare management - The children in our target area have working parents and many spend significant time in childcare or recreational activities. The children, their parents, and childcare staff all requested increased education for childcare sites.
- Improving community awareness - All stakeholders cited the importance of increased knowledge at all levels in the community. All expressed a desire for uniformity of information from all who support families and children with asthma and frustration with inconsistent information.

3. Develop an intervention plan

An intervention action plan was developed and approved by the RWJ National Program Office and is currently in the process of being implemented. The plan was guided by the priorities outlined in the previous section. The intervention took shape over a compressed time frame with a series of planning retreats to get committee and community input. The action plan will use multiple strategies at the levels of the home (which includes child and family), clinic, school, childcare site, community and institution (including policy makers).

It is believed that combining multiple strategies in a coordinated, multi-level approach within a single community has a greater likelihood of impacting community asthma morbidity than isolated, single-focus efforts or efforts diffused over a larger area.

[1] The Healthy Homes I and II Projects are NIH-funded randomized trials of an outreach intervention to reduce exposure to indoor asthma triggers. Participants are similar to the target population.

Children from the geographic catchment area with asthma and their parents will be recruited for these activities from participating clinics (using clinic encounter data to identify children with asthma), schools (identifying children through school health forms and school nurses), childcare sites, pharmacies and community organizations in the high intensity neighborhoods, hospitals and emergency departments serving the residents of the neighborhoods (using monthly administrative data reports), and self-referrals generated by word-of-mouth and local publicity.

Improving Asthma Self-management

- Community health workers: Education and support for asthma education will be provided in the home by two Community Health Workers (CHW's) funded by AAA, three additional CHW's supported by Healthy Homes-II and one additional CHW funded by the City of Seattle. Each CHW client will receive two to five visits over a one-year period to assess home environment and asthma self-management practices and to support families in improving home environmental quality and self-management. Each CHW will work with 80-100 households per year, for a total of 1000-1250 households over a 2.5-year period.
- Asthma management coordinator: A 1.0 FTE nurse (80% funding by AAA and 20% by the City of Seattle) with public health and care coordination experience will provide clinical back-up to the CHW's and coordinate client asthma management across CHW's, schools, childcare sites and clinics. The coordinator will assure that each client has an asthma action plan which is shared by providers. When a plan does not exist, she will assist the provider in developing one. She will suggest referrals to community resources in conjunction with the CHW's. She will work with 200 clients per year.
- Asthma nurse educators: Healthy Homes-II will support clinics in providing this service to 80-100 children in the AAA target area per year for three years, with most children coming from the high intensity neighborhoods.
- Community-based asthma education: AAA will also offer small group education, using the Asthma Care Training (ACT) model, to 700 families over three years.
- Pharmacies: Long's Pharmacy, a major regional chain, will provide KCAF/AAA educational materials at its two stores in the high intensity neighborhoods; accept patients referred to them by clinicians for medication reviews, apparatus training, and other asthma management activities without charge; train staff on asthma management using KCAF/AAA protocols; and refer clients to community asthma resources based on a list provided by KCAF.
- Public health nurses: Public health nurses already visit with families and assist them with asthma management including asthma education and home environmental assessment. The KCAF/AAA will provide them with additional materials and referral sources and will assist them in care management as they collaborate with participating providers, schools and pharmacies.
- School nurses: School nurses will identify children who can be included in the project, coordinate the school's role managing asthma, work with school staff to advocate for systems that enhance the well-being of students with asthma, act as a conduit for asthma management information, and work closely with Team Asthma Goes To School (TAGS). We will also work with school-based clinics in middle and high schools to promote detection, education, and care coordination.

Improving Control of Home Environmental Triggers

The primary intervention in this area will be in-home visitation by CHW's using methods adapted from the Healthy Homes project:

- Home environmental assessment: The CHW will conduct an initial comprehensive home environmental assessment and repeat selected items at subsequent visits by interviewing clients and inspecting the home, and
- Home environmental action plan: The CHW will provide education on identification and reduction of indoor asthma triggers and work with each client to develop an individualized set of actions to improve indoor environmental quality.

Improving Clinical Management

- AAA will support 0.15 FTE of a clinician-leader's time at each site to serve as the clinic asthma champion. Additional support for champions will be available through the AAFA ACT project ($5000 for two clinics and $2500 for two others). The champion will lead a team effort to implement the PDSA process and incorporate improved practices into clinic operations. Champions will receive technical support from the KCAF asthma management coordinator and the two asthma management consultants.
- Registry: AAA will support development of an asthma registry at four sites and the City of Seattle at two sites through provision of computers, software, technical assistance and funding 0.1 FTE registry manager (who will enter data, prepare reports and add registry data to clinical charts).

Improving School Management

- KCAF/AAA will provide asthma control support to schools through TAGS. Team Asthma will offer education of students, parents, and school personnel; assessment of indoor environment for triggers; referral to a CHW and/or public health nurse; and consultation regarding best management of individual students with asthma.

Improving Childcare Management

To respond to provider interest in further education and assistance for caring of children with asthma, AAA will support and enhance existing KCAF member activities:

- Provider training and education: AAA and Environmental Protection Agency (EPA) funds will support the Asthma and Allergy Foundation of America-Washington (AAFA-WA) in hosting 25 trainings per year for providers serving children from the high intensity neighborhoods through its "Asthma and Allergy Essentials for Child Care Providers" program. KCAF/AAA will support 1-2 additional larger trainings a year through the PHSKC Childcare Program so that childcare providers can attend without charge and receive required continuing education credits. A total of 650 providers will receive training.
- Provider consultation and support: PHSKC has 12 public health nurses who make 2500 visits a year to childcare sites. The nurses will accept referrals from KCAF/AAA for providing environmental assessment, education and referrals for additional resources.

- Asthma screening: Providers will be instructed in how to screen clients for asthma using a simple questionnaire and will refer those who screen positive to the asthma management coordinator for further follow-up.
- Childcare for children during asthma exacerbations: In response to needs expressed by working parents and the high frequency of school absences due to asthma, we may explore working with 1-2 childcare centers to offer care and basic tutorial services for children with asthma exacerbations that prevent them from attending school.

Improving Community Awareness

Data from the focus groups and key informants indicated that community members place a high priority on community awareness and education. Local experience of coalition members also reinforces the value of such efforts. The community awareness campaign will include:

- Asthma Awareness Van: Local funding will be sought for a van to contain a desk for outreach workers, audio-visual equipment, educational materials, and computers for running interactive asthma educational software.
- Targeted outreach: The community organizer and health educators will visit 25-30 community based organizations, agencies, and faith institutions annually. The outreach worker will learn about their interests and activities and invite their participation in activities such as conducting asthma workshops, holding asthma seminars, developing asthma support groups for caregivers and youth, and organizing community health fairs.
- Media: The Communication Action Team will actively pursue relationships with the media, especially radio that aims at the Vietnamese and Latino communities and community newspapers that have wide distribution.
- Asthma theater: AAA is pursuing a relationship with several local theater artists who work with children and adolescents. The play will be adapted and translated by bicultural students for presentation to culturally diverse audiences.
- Community events: The outreach coordinator and health educators will participate in 12 community events per year, setting up a KCAF table and providing educational materials, information and referrals. AAFA-WA will similarly participate in 2-4 health fairs per year.
- Pharmacy-based promotion: Participating pharmacies have agreed to display asthma education brochures, insert them in bags when processing prescriptions and to display posters. Additionally, a participating pharmacy may host a mini-health fair with support from the van.

Improving Coordination Across Levels

An overarching goal is to coordinate and link these level-specific activities with each other to take advantage of opportunities for synergy and reinforcement. Coordination will occur through the following mechanisms:

- Continued dissemination and refinement of the intervention plan so that all stakeholders are aware of and have the opportunity to shape the plan.
- Continued development of the KCAF coalition as a vehicle to bring stakeholders together to identify opportunities for collaboration and coordination.
- Development of explicit referral protocols across levels.

- Development of a common asthma action plan (which is a plan of care for each child) for use by schools, clinics, community health workers and childcare sites.
- Development of common educational resources to promote delivery of consistent, reinforcing health education messages.
- Promoting a consistent and unified approach to asthma from the child and caretaker perspectives.

Promoting Asthma Control Policies

Several policy goals have been identified that would promote diffusion and sustainability of action plan activities. During year one, the feasibility of success in reaching each goal will be evaluated and the two or three most promising ones selected as the focus of advocacy work in years two and three. The goals aim at the following:

- To promote coordination of care and services through creating access to common client-specific asthma-related health data. AAA will explore the possibility of moving the site-based asthma registries to a web-based platform so they are accessible to a limited set of authorized service providers.
- To promote cultural competence in asthma care. AAA will collect information and materials from providers that have successfully worked with diverse ethnic groups regarding asthma management; review them with representatives of our primary ethnic groups (Latino, Vietnamese, African American) and other groups as time permits; synthesize them into locally acceptable guidelines and resources for providers, caretakers and children; and disseminate them.
- To develop funding mechanisms to support care coordination, self-management education/support, and other system components. For example, AAA has begun working with our state Medicaid agency to include coverage for allergy control bedding encasements.
- To promote school policies that support students with asthma. Through the Asthma Management in Educational Settings (AMES) program, the Forum will encourage schools to examine their policies related to availability of medications and the ability of school personnel to act quickly and appropriately when a student is having asthma symptoms.
- To promote policies in the housing sector which support healthy home environments for children with asthma. We will continue our work with the Seattle and King County Housing Authorities to identify households with children with asthma who would benefit from relocation to healthier units and to incorporate healthy homes concepts into renovation of existing units and construction of new units.
- To expand asthma surveillance activities as a mechanism to increase community awareness and monitor trends. We have begun efforts to collect emergency department asthma encounter data for King County. The two largest departments are currently providing these data and we will enlist others through individual contacts and a meeting of emergency department directors (the Medical Director of Harborview Medical Center has agreed to sponsor this effort).

Coalition Development

The goals of the coalition development effort are to:

- Increase CBO and parent/child involvement in KCAF activities through the community outreach team and outreach coordinator,
- Expand the leadership of the coalition through broadening the steering committee and sharing leadership responsibilities. The addition of a full-time coalition coordinator will provide capacity to support this leadership development process, and
- Increase visibility of the KCAF and its activities through implementation of the CAT plan.

4. Evaluation of AAA planning process

The three objectives for AAA during the planning year all related to the intervention planning process, including gathering community data input, setting priorities, and developing a detailed intervention plan for the additional three years of RWJ funding. This section assesses the quality of the planning process from the perspective of the participants, using information from the key informant interviews with KCAF members.

Most informants were satisfied with the way the process was organized and carried out, particularly with the effort to provide opportunities for input:

Members had plenty of chance to give input. People were for the most part open-minded.

The process was very "open", with a large number of meetings. As a result, the process was very exhaustive.

A real effort was made to be inclusive of all areas that impact asthma. It was just not possible though, considering budgetary and time constraints.

The July retreat allowed people to really say their piece – a lot of people shared and the results reflect group consensus.

We made a great effort to ensure that all felt represented.

For those community members who did participate, we made sure their voices were heard and their ideas were incorporated into the plan.

We really made an effort to connect with community members.

There was also a high degree of satisfaction with the organization of the process:

Seemed well organized with a lot of planning.

Subcommittees would take their plans to the KCAF for input, ideas, etc., so there was good overlap and coordination.

Each committee was given time and a budget to develop their own set of interventions. It was well coordinated and all areas got be heard this way.

There was a high level of enthusiasm and care given to the process.

Despite general agreement that strong efforts were made to include community residents and community-based organizations in the planning process, many informants felt that these efforts had not been successful.

I am nervous about the amount of community involvement we have. The clinical piece will not be hard to convey because we are largely clinicians ourselves and speak the same language. But when we get to the community people, they are not going to get it, because they have not been a part of it, and we are not like them. So, those people who are the most unlike us, I am the most concerned about.

Getting more voices from the community. I don' have any suggestions as to how to do that. We have not really heard from children with asthma or from parents of kids with asthma. We tried to get their input, but were unsuccessful. Perhaps more time, money, and planning would have helped. We were naïve about what it would take.

We need more people from the community to attend. Representation from those groups in the community who would have an interest is not there. And, I worry that we are becoming even more "set" as a group as time goes on.

It was difficult getting community people involved in the process. Moving meetings out into the community was a good change. I think the meetings were very scary for community members; locations were tough too, when they were not being moved around. So, the coalition members had plenty of chance for input, but not the community. The community asthma summit meetings did not work well. We need to figure out other ways to get the community involved – possibly plug into existing groups.

Outreach to the community. Most of the people involved in the planning process were those who are connected to asthma in some way through their work. More efforts to include community organizations and community residents were needed.

Not enough representation from the community. We needed to entice community members to come. We could have given certain community groups chunks of money and let them do some of the work in helping us get their groups more involved. Some communities viewed us as the "whites coming in and trying to do something to our community".

The SC needs a more diverse group. It does not represent the group we are targeting in our interventions for AAA. Getting these people involved would empower them to be more committed. The SC meetings are too long for Community based organizations to attend. It is not realistic to expect them to attend meetings this long.

The lack of community involvement was seen by some informants to have resulted in a concentration of leadership in the health department and clinical providers, which in turn made the plan more narrowly focused on clinical care:

More emphasis should have been placed on getting the community involved at the leadership level. We do not have a diverse leadership group; it is mostly doctors and researchers.

I would like to see more feedback from the community and from others who are not either health care providers or from the health department.

The KCAF members had good participation, but there are other sectors that are also important to asthma control that we missed, such as insurers, hospitals, and some clinicians.

An additional problem with the planning process was the lack of staff, which resulted in burnout for the volunteers doing much of the work:

Massive amounts of work done by just a few people, which resulted in burnout for those few. The work could have been more equally shared.

We needed more time – it was a lot of pressure and very intense. I was only supposed to be working 20 hours a week but I put in my own time on top of that to meet the deadlines.

Having more paid staff time. Many of us had to do this work in addition to our full-time jobs. Writing and meeting took a lot of time. Hopefully, the mundane, minutiae sorts of things can now get the attention of the paid staff.

Staffing resources. Things were not getting done, and were not getting forwarded there was a lot of backtracking and therefore frustration, mainly at the staffing level. Sharing the Healthy Homes admin. staff seemed like a good idea but then turned out to be a mistake. They were pulled in too many directions. The amount of time to plan was too short and there was one group we missed – primary school kids and parents. We need to work on this group, get more feedback from them.

The key stakeholders should have been funded during the planning process so that they could provide more input. Broader representation of those working in asthma was needed and to rely on them volunteering their time is not very realistic. Too much emphasis was placed on volunteerism.

In summary, the AAA planning process was seen by participants as well organized, with a sincere attempt to gather broad community input. The effort to involve residents in the planning process was largely unsuccessful, but key informant interviews and focus groups with residents were a valuable tool for soliciting input. Additionally, it was perceived that a lack of staffing resulted in a few individuals having to shoulder a majority of the planning process workload.

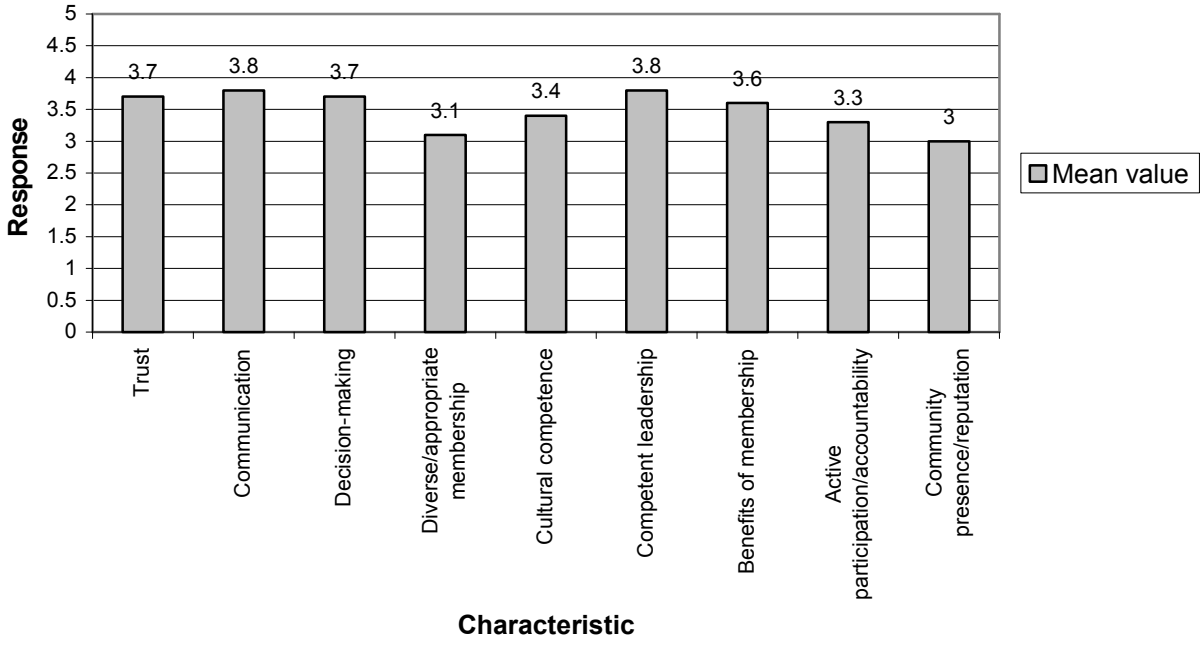
B. King County Asthma Forum

1. Attain the characteristics of a successful coalition

A community-based health coalition such as the King County Asthma Forum is ultimately judged on how well it succeeds in developing and carrying out an action plan that leads to community health improvement. This judgment can only be made for AAA/KCAF after several years of operation. However, there are a number of characteristics of successful coalitions that have been identified that permit an intermediate assessment of KCAF. These include building of trust among members, effective communication and decision-making processes, diverse and culturally competent membership, effective leadership, an established community presence and a perception on the part of participants that benefits from participation outweigh any costs.

A closed-ended survey of coalition members was developed to assess the characteristics of successful coalitions. Figure 1 shows summary scores for the major dimensions (**Appendix B** includes results for all survey items). The results are similar to the key informant responses concerning the AAA planning process. In particular, satisfaction with communication, trust and leadership of the coalition were relatively high (rankings of 3.7-3.8 on a 1-5 scale), while items related to community involvement - diversity of membership, community presence - were rated lower (3.0-3.1).

Figure 1: Satisfaction with Coalition Characteristics



Key informants were asked to assess strengths and weaknesses of the coalition. A number of respondents listed the main strength as the commitment of the members, including how much they care about their work and each other and their willingness to set aside personal and organizational goals for the broader good.

> *The people are really committed to asthma and care about it. Everyone is trying hard; people are committed to discovering and halting the epidemic in the two critical areas.*
>
> *I like the people who participate. They care.*
>
> *I am impressed by the energy and passion/enthusiasm members have. They are determined and are willing to put in time.*
>
> *The group is congenial and works well together. We are free of acrimony and disputes.*
>
> *People are willing to work cooperatively and have worked to fit their organization into the whole of the forum. I feel ownership.*
>
> *Good people, low ego factor.*

When asked about benefits from participating in the coalition, most informants focused more on the opportunity to be part of a larger effort benefiting the community rather than particular individual or organizational benefits.

Asthma management is complex and substantial with a lot of sequelae in terms of quality of life. Given that, it takes a broad base of understanding, focus, and intention to change the current status quo. I believe that the KCAF provides that broad base, and brings to the table diverse players.

It is a great opportunity to build a strong movement. KC also has a lot to offer the rest of the state.

Collaboration results in a much richer product than what each individual can accomplish on his/her own. This is the strength of the forum.

Responses to the question about KCAF weaknesses focused primarily on the recurring theme of a lack of community representation.

Not enough diversity, either culturally, professionally, or from the community.

The forum does not have the broadest representation. I have a fear that those who do attend are becoming "elitist". And, there are not enough patients and families on board.

There is little if any community base.

As the steering community we are not as rooted in community-based organizations as we would like to be. But sometimes this is an elusive and idealistic goal, but we always want to keep it on the table and keep striving for it.

Everybody is pretty similar in work background and culturally there is not enough variety and diversity.

The forum does not have the broadest representation.

An additional weakness during the planning period for the coalition was a lack of adequate staff resources:

Lack of support staff. There has been too much work for too few people.

Lack of formal staffing has been a weakness.

The whole effort has been primarily based on good faith efforts of volunteers. We have had very little staffing to date.

The voluntary nature of the forum. People can give only a certain amount of input if they are acting voluntarily.

Another weakness that emerged was around governance and organizational structure. Common themes focused on lack of clarity between Allies and the Forum, as well as loose boundaries between the two; difficulties integrating various asthma projects associated with the Forum; and a lack of clarity of the respective roles of the committees and projects.

It (Forum) is still evolving. I approve of the recent decision that was made about all subcommittees are subcommittees of the Forum and each will have at least one AAA member on board. This will allow the subcommittees to retain a broader perspective of the KCAF and therefore focus on the entire county. Before this decision was made, it was very unclear where our responsibilities and time should be spent. But, this is the natural evolution of the coalition.

This (integration of various projects) is a very critical area and is unclear. No one reality seems to exist that we can all agree upon. The coalition must do something about this, so we are all able to see the same reality.

There is disagreement between project members and steering committee members regarding who controls what and on which projects, who should be part of the decision-making, and who should jump through which hoops of getting steering committee approval, while other projects can seemingly do whatever they want.

In summary, KCAF has many of the characteristics of a successful coalition, including trust among members, and a clear action plan. The current members of the coalition clearly like and respect each other. The major weaknesses are that a broader cross-section of the community needs to become involved in the work of the coalition and that the governance structure may need further refinement including further examination of the boundaries between Allies and the Forum, the integration of Forum projects, and the roles and purposes of the various subcommittees.

2. Have functioning committees

As part of the governance structure adopted by KCAF, several standing committees were established, including:

- Education, Outreach, and Environment,
- Parents and Community,
- Schools,
- Clinical,
- Evaluation, and
- Governance.

The majority of the standing committees established a consistent time and date for holding meetings. A current meeting schedule was posted on the KCAF website and a meeting announcement was sent electronically to all KCAF members. Meeting minutes were distributed via e-mail to all KCAF members following a meeting. A meeting attendance log was maintained that listed all the meetings and identified who attended. During the planning year, approximately 74 meetings (either forum or subcommittee) were held, not including summits, special meetings, or teleconference meetings.

The committees had a number of concrete achievements during the planning year. The Schools Committee completed review of the American Lung Association's *Asthma Management in Educational Settings* manual and is assisting in its dissemination. The Parent and Community Committee facilitated ten focus groups, piloted a support group for the Vietnamese community, and were invited to conduct asthma education and support at a school. The Education, Outreach and Environment Committee completed a literature and policy review on Medicaid coverage of bedding covers and are completing a childcare education curriculum. For a list of major coalition and committee accomplishments during the planning year, see **Appendix B**.

The Clinical Committee designed a fact sheet for a potential Q&A page on the KCAF website. In addition, coalition members have demonstrated capacity for implementing a wide range of effective programs, such as Asthma Management in Educational Settings, Community Health Plan of Washington's asthma care coordination project, or Public Health – Seattle & King County's (PHSKC) Healthy Homes-I project (a randomized, controlled trial of the effectiveness

of CHWs on reducing exposure to indoor triggers and asthma morbidity among low-income children).

3. Increase community participation

The objective of increasing community participation focused on including families affected by asthma, community groups, and faith communities. Despite strong efforts on the part of the coalition, the objective of getting significant resident participation has not yet been achieved. The relative lack of community participation has already been discussed above (under the evaluation of the AAA planning process and characteristics of a successful coalition). This section examines some of the reasons for the lack of community participation.

Table 1 shows a more detailed breakdown of the coalition survey items related to participation (complete survey results for all items are in **Appendix C**). The two lowest-rated items related to resident participation and level of influence of residents; respondents also rated diversity low. Trust among members was seen as high and the coalition was viewed as welcoming, but these had yet to translate into getting additional resident members.

Table 1. Coalition Survey Items Related to Community Participation

	Mean
Satisfaction (1-5 scale) with:	
◊ Participation of influential people from key sectors of the community	3.2
◊ Participation of community residents and community-based organizations	2.6
◊ Level of influence community residents and CBOs have within the coalition	2.8
◊ Diversity of coalition membership	3.0
◊ Trust shared by coalition members	3.7
◊ How welcoming the coalition is to new members	3.9
◊ Efforts to promote collaborative action	3.9
◊ Degree to which members are involved in making decisions	3.8
◊ Giving the community help in meeting the community's needs*	3.4

One barrier to getting resident involvement in the coalition was the tension between the systems-level clinical changes sought by both national AAA and the clinicians on the KCAF, and the more practical everyday concerns of parents of children with asthma.

> *There was a built-in tension between those who get paid to do this professionally and those who are users/patients, who do other jobs 40 hours a week. Many efforts were made to blend these two points of view – but this tension was a limitation to our progress.*

> *The clinical piece will not be hard to convey because we are largely clinicians ourselves and speak the same language. But when we get to the community people, they are not going to get it, because they have not been a*

part of it, and we are not like them. So, those people who are the most unlike us, I am the most concerned about.

In addition, community residents were less able to set aside the time to attend meetings:

It was hard getting parents of children with asthma involved, which was not surprising given the large chunk of time the meetings took. They have other competing priorities.

Asthma is not a glitzy, popular topic. Our target populations have a lot of other issues in their lives to deal with and are usually families that are struggling in a lot of ways.

Clinicians, even though most were also volunteering their time, had greater motivation to participate since their work is tied to asthma. As one respondent said:

However, my time was limited by the fact that this was volunteer work for me, so I was not always able to provide as much input and be as involved as I would have liked. Those people whose participation was part of their work were probably more able to provide input than those people who were volunteering their time. There had been talk about providing stipends to people who were volunteering their time, but in my case that would not really have made a difference - for me, it was more of a time conflict.

Key informant respondents had a number of suggestions for increasing resident involvement:

Identifying focus groups within different communities or neighborhoods — trying to identify folks in that way. Soliciting input more directly through school settings — parents of kids who suffer from asthma.

I think going through places where there's primarily oral communication – churches or shopping centers or whatever – may be the best way to go.

They need to be very clear about the benefits to the community-based organizations. They need to identify what KCAF has to offer agencies when they come to the table. They need more recruitment and more visibility in the community.

They need to go out and do informal and formal presentations to community agencies, community churches, and community organizations. Relate how [the coalition] involves them as a person and as a community.

We need to go to the programs where community residents have had a strong role, like the Odessa Brown Clinic's Outreach Program. If you want their voice, then going to programs that include them as active participants is a way of bringing them into the Forum.

Keep reaching out because it takes a while. This isn't an easy thing to do. Our traditional health care system is not diverse and is not representative of the people who have the greatest need. To change that is not easy. They need to keep reaching out — keep going to churches and other non-traditional sources. For example, since the African American community is a target community, target all churches in King County, which are African American based. I think they're doing that already. And they should do more. Also they should target community leaders and talk to them about what's going on.

We need more Vietnamese representation at KCAF — Vietnamese doctors, nurses, and teachers — need to enroll more Vietnamese people. AAA should get more involved with low-income people. AAA should do different ethnic language asthma translation materials to educate different ethnic people in their language.

They could have an asthma club, where people who have asthma would automatically be members. This group would meet like a support group and talk about how they handle different episodes and how they keep their quality of life improved in spite of the asthma.

Perhaps we should try and create a big presence in the community one week prior to a forum meeting, with food and videos for kids. Or, have focus groups. We need to be asking the community members how and in what format they feel most comfortable being involved. Do they prefer big groups, or smaller groups? We really need to ask them directly what methods they prefer.

We need to meet people where they are at – we must talk with people and build relationships. Having various lecture topics at the quarterly meetings may be a draw. We need to get input on what the community wants and is interested in.

Serious outreach is needed where we sit with people and also invite them in. Examples of groups we need to connect with are the Urban League. I think we try to focus too much on the health-related areas and not on other avenues to reach people, for example, the youth theater groups. Or getting business people involved, etc. We are too tunnel vision, focused only on health, when trying to reach the community.

4. Establish community presence and reputation

KCAF must establish a strong community presence in order to recruit families into the interventions, build better ties to community-based organizations and improve prospects for sustainability. KCAF carried out a number of activities to increase its visibility during the planning phase. This section reviews those efforts and summarizes the community awareness activities planned for the intervention phase.

The King County Asthma Forum continues to maintain a website that highlights the Forum's purpose, goals, and objectives, a list of forum activities and meetings, existing committees, current projects, a participant directory, asthma reports and facts, how one can get involved, and helpful links. Frequent electronic messages are sent to all meeting attendees that include meeting minutes, announcements about upcoming events, students looking for applicable internship experiences, and other pertinent information. In addition, a descriptive brochure was developed, and a logo was designed and utilized both as letterhead and for brochures/handouts.

The following are some other accomplishments that have helped establish a presence and reputation within the community:

- The Clinical Committee developed a fact sheet for a potential Q&A page on the website.
- Two press releases were published, one when the planning year grant was awarded, and one when the implementation grant was awarded.
- One community presentation was made at a school in the targeted intervention area to inform community members about the planned interventions and to get feedback.
- The Parent and Community Committee piloted a support group for the Vietnamese community, which resulted in an invitation to conduct asthma education and support at a school.
- The Schools Committee completed review of the Asthma Management in Schools guidelines and is assisting in its dissemination.
- The Education, Outreach, and Environment Committee completed a literature and policy review on Medicaid coverage of bedding covers and are in the process of completing a childcare education curriculum.

- A press conference was held at the Central Area Health Center on January 30th. The conference highlighted the awarding of the Allies grant to the KCAF. The news was also released in both local and national newspapers the day before the press conference.

Despite these efforts, community presence was one of the weaker areas cited by coalition members. Community presence was the lowest rated of the constructs in the characteristics of effective coalitions (see **Figure 1** in section 1 above). This assessment was supported by comments from key informants:

I think we under-utilize the media and do not promote what we are about to the community in an effective way.

More media coverage of project is needed.

I have not seen media involvement yet.

[Use of media]: just not there yet – will get these if given 3 years and time (?).

[Use of media and communication between coalition and broader community]: are a function of lack of skilled staff and overworked volunteers.

- The low level of media exposure was partly due to the fact that the focus during the planning phase was internal (i.e., gathering community input and planning the interventions). Now that the interventions are being implemented, more media efforts and outreach will occur, with the purpose of increasing community awareness of asthma and of recruiting people into interventions and Neighborhood Asthma Committees.

5. Increase cultural competence among KCAF members

KCAF places a high value on cultural competence and devoted the April 2001 quarterly board meeting to cultural competence training. Thirty-one people attended. The training focused on how to empower communities, and some guiding principals of how to be culturally sensitive were discussed. Several strategies geared toward recruiting and retaining ethnically diverse members were developed. It is somewhat difficult to judge cultural competence of KCAF since as has been noted repeatedly the current makeup of the coalition is not very ethnically diverse. The inability to increase the diversity of the coalition may in itself be a sign of a lack of cultural competency -- i.e., the ability to attract and welcome new members from other ethnic groups, particularly community residents. For example, aspects of cultural competence include eliminating clinical jargon and holding meetings at places accessible to community residents. Several key informants mentioned that minority residents came to one meeting and then didn't return:

I think the meetings were very scary for community members; locations were tough too, when they were not being moved around.

Our meetings are too technical or boring for a community member or organization to participate in effectively.

When asked directly in the key informant interviews about the cultural competence of KCAF, most respondents were unsure:

> *I'm not the right person to judge their cultural competence; I don't know. They have some work to do to involve non-English speaking members (the target group) to the board. I don't know realistically how they can do that.*
>
> *I don't have a sense of how culturally competent it is. That's a problem in just about every endeavor in this city because of the diversity. And there's always room for enhancement.*
>
> *I don't know how culturally competent they are. I know they sponsored a course in cultural competency that I couldn't go to. I think that's a good way to start.*

Respondents also had suggestions about how to increase the level of cultural competency:

> *I'd like to see more interpreters at meetings, slow the process down so that it can be explained to non-English speaking participants. It may not be practical with the timelines and tasks ahead — it's never built into the grant — but I think it's probably a barrier.*
>
> *It's also good to encourage continuous feedback from stakeholders and members of target groups that they're interested in connecting with.*

Getting experts like the folks at the Cross Cultural Center to review the activities and suggest ways to bring in different ethnic and cultural groups. We have some resident experts in town and soliciting their help would be a key activity.

IV. Summary/Lessons Learned/Update

King County Allies Against Asthma achieved all of the major objectives it set for itself during the planning year, including carrying out an extensive needs assessment process, setting priorities, and developing an intervention plan. The King County Asthma Forum was also largely successful in achieving its major objectives, including strengthening itself as a coalition and developing functioning committees. The major weakness identified for both AAA and KCAF was a lack of community participation in either the KCAF coalition or the AAA planning process. A coalition weakness that emerged was a lack of clarity around issues of governance.

Key lessons learned during the planning year included:

- Governance structures evolve over time. Coalition development and creation of an effective governance structure is an evolutionary process. As the Forum continues to refine its work and its interplay between Allies and other coalition projects, the governance structure will need periodic assessment to ensure it continues to optimally support the work;

- Membership recruitment is challenging during a planning process. Expecting active growth of coalition membership during the planning year is unrealistic. It is difficult to engage new members without tangible activities that clearly benefit them. The recruitment and retention of CBO's and target communities is particularly difficult for a health improvement project during the planning phase;

- Difficult to organize interventions in large, diverse neighborhoods. The geographic diversity and breadth of the target communities inhibits the ability to deeply penetrate a neighborhood with organizational efforts and may require designing several innovative methods for sharing and disseminating information;

- Multiple, creative recruitment strategies are required. Participation and membership needs to be broadly defined with multiple points of entry into activities. In other words, we need to continue developing innovative avenues of participation that do not require attending formal KCAF meetings (e.g. KCAF presence at community events and meetings of community organizations, interviews, participation in field activities). In order to recruit families into the projects and interventions and build stronger ties to the community, media efforts may need more emphasis as interventions are rolled-out, and increased collaboration with already existing community activities and organizations may provide more direct lines of communication;

- Effective community-based planning takes time. One year is not an adequate amount of time to conduct a community-based planning process with the purpose of developing a health improvement project. Building relationships in targeted communities takes time and may be impeded by language and cultural barriers and potentially negative previous experiences with community-based programs and/or research projects; On the other hand, the intensity of the process and a definitive timeline required that stakeholders work closely together, resulting in the formation of durable relationships built on trust and mutual respect.

- Developing a comprehensive intervention strategy requires a planning team with diverse perspectives and areas of expertise. There was a good balance on the AAA planning team between members with knowledge of evidence-based research in asthma and those who understood the needs of the targeted communities

- Paid staff is critical for success. Adequate staffing is critical in the early phases and beyond to facilitate penetration into a community while simultaneously meeting the complex demands of the funding agency and the local stakeholders.

Update

Since the Planning Year Report was completed, KCAF has taken steps to address several of the challenges outlined in this report. The following is a brief summary of those activities; a more comprehensive update will be provided in the upcoming evaluation report covering the initial implementation year (January 1, 2002 through December 31, 2002) will be written in the coming months.

Lack of community representation and involvement in the planning process and the Forum organizational structure

Many of the suggestions mentioned by key informants for increasing resident involvement have been adopted by KCAF:

- Meetings are being rotated to a variety of community sites, including potential community partners.

- Five Neighborhood Asthma Committees are being established that bring residents together to talk about their concerns.
- Coalition stakeholders that have participated in the past in KCAF activities are being contacted individually and updated on recent developments.
- KCAF/AAA staff are attending meetings of community-based organizations and describing how Forum participation might benefit the organizations.
- The Forum hosted a workshop on fundraising and sustainability for community-based organizations.
- Each Steering Committee member was asked to contact and invite at least two new people to attend a committee meeting and learn more about the KCAF.
- An orientation packet was developed and each person who attends a forum meeting receives a welcoming telephone call from either the KCAF Chairperson or an AAA staff member.

Need for functioning governance and organizational structures, and committees; lack of clarity and loose boundaries between the KCAF and its projects

- The Governance committee continued to meet after the planning year ended to address issues related to organizational structure and governance. Some committees were disbanded, some were merged, and others established new goals and objectives.
- A Cross Project Coordination committee was formed to coordinate Forum projects, increase communication, and encourage working relationships across the projects.
- A Steering Committee retreat resulted in several significant proposed changes to the by-laws, some of which have been approved, and some of which are currently under discussion.

Modifications and changes to the Intervention Action Plan that have occurred since the Planning year:

- The plan to have selected pharmacies provide asthma education has not been implemented, partly because of issues around pharmacist reimbursement for educational services and partly because KCAF lost its key pharmacist member who was coordinating this effort. However, another pharmacist has been recruited and there are plans to re-visit the pharmacy education program.
- A "Learning Collaborative" has been created involving five clinics that serve the target communities. The Learning Collaborative is implementing a system-wide model of care that focuses on assuring the delivery of evidence-based care and the provision of strong support for family education and self-management.
- Daycare provider training, education, and consultation have begun; however, facility environmental assessments have not been implemented. Many smaller, privately owned centers are fearful of having to make costly environmental modifications. Instead, an educational component on the environment has been incorporated into the provider training, and individual facility assessments are available upon request.
- Funding for the provision of an asthma awareness van has not yet been sought. There are plans to re-visit the idea in January 2003 and the interest and potential for adding this intervention still exists. Plans to write and produce a play about asthma that will be performed by youth were carried out during the Implementation year 2002 and the play is slated to be performed during 2003.

Need for increased cultural competency

Efforts to increase the diversity and cultural competence of the coalition have focused on reaching out to CBO's through presentations on the work of the Forum and to residents through the five NAC's in the targeted communities. In addition, Forum meetings were re-structured in part to be more "resident-friendly" by featuring an educational component geared toward community members.

Need for a coordinated effort to increase the visibility of KCAF/AAA

The Communications Action Team was disbanded following the hiring of AAA staff that was expected to fill that role. However, since staff has been working primarily on intervention development, KCAF is discussing the possibility hiring a public relations firm to increase coalition visibility and help carry out the communication plan. In addition, the Schools Committee is developing a multi-article proposal to the Seattle Times (local newspaper) on asthma and schools.

V. Appendices

Appendix A: Allies Against Asthma Grantees

1. Milwaukee Allies Against Asthma Coalition
Project Director:
John R. Meurer
8701 Watertown Plank Road
Milwaukee, WI 53226-0509
Phone: 414-456-4116

2. Allies Against Asthma Workgroup
Consortium for Infant and Child Health (CINCH)
Project Director:
Cynthia S. Kelly
855 West Brambleton Avenue
Norfolk, VA 23510-1005
Phone: 757-668-6443

3. Philadelphia Allies Against Asthma Coalition
Project Director:
Robert J. Groves
260 South Broad Street
Philadelphia, PA 19102-5085
Phone: 215-731-6151

4. Long Beach Alliance for Children with Asthma
Project Director:
Elisa Nicholas
2801 Atlantic Avenue
Long Beach, CA 90801
Phone: 562-933-0430

5. Alianza Contra el Asma Pediatrica en Puerto Rico
Project Co-Directors:
Nicolás Linares
P.O. Box 365067
San Juan, Puerto Rico 00936-5067
Phone: 787-758-2525 x4102

Marielena Lara
1700 Main Street
P.O. Box 2138
Santa Monica, CA 90407-2138
Phone: 310-393-0411 x7657

6. King County Asthma Forum

Project Director:
Jane Peterson, RN, PhD
Professor
School of Nursing
Seattle University
Seattle, Washington
206-296-5682

Project Co-Director:
Jim Krieger, MD, MPH
Chief, Epidemiology Planning and Evaluation Unit
Public Health - Seattle and King County
First Interstate Building, Suite 1200
999 Third Avenue
Seattle, WA 98104-4039

7. D.C. Asthma Coalition

Project Director:
Carol Hill Lowe
475 H Street, N.W.
Washington, DC 20001-2617
Phone: 202-682-5864

Appendix B: Planning Year Accomplishments

Accomplishment	*Description*
Coalition Development	
Increased coalition membership	• Membership of KCAF increased by 62% during 2001 (from 44 individuals representing 29 organizations to 71 individuals representing 45 organizations). • Membership was increased through key informant interviews, meetings with community leaders and key organizations, community summits and focus groups.
Adopted formal governance structure	• Leadership is provided by the Steering Committee, which meets monthly and makes decisions and provides operational oversight for projects sponsored by the KCAF. • Expanded size of steering committee. • Standing committees include Education, Outreach and Environment; Parents and Community (aka Neighborhood Asthma Committee); Schools, Clinical; Evaluation; and Governance.
Brought in/applied for new projects	• NIEHS-funded Healthy Homes-II. • AAA Intervention Phase (application submitted and received). • CDC Asthma Education Grant (application submitted and received). • HUD Healthy Homes (application submitted and received).
Community Outreach	
Community Summits	• Two Asthma Summits were held (in Seattle and Tukwila). Approximately 30 families attended both summits. • Each summit had an educational presentation followed by three breakout sessions in English, Vietnamese, and Spanish.
Focus groups	• Ten focus groups of key stakeholders were conducted at various locations in King County, including three parent groups, two youth groups, and five provider groups. • Designed to generate ideas for AAA interventions.
Member key informant interviews	• Interviewed 16 members of the KCAF to collect information related to coalition development, priorities, strengths, and challenges.
Non-member key informant interviews	• Interviewed 13 key informants who were not members of the KCAF at the time of the interview to include more stakeholders in the process. • Selected to represent diversity of target populations and stakeholders.
Meeting location	• Meetings were moved out into the communities we serve.
Community presentations	• Brought the interventions back to the community (Aki Kurose), solicited suggestions, got feedback, and answered questions & concerns about proposed services.
Other Activities	
Asthma Management in the Educational Setting (AMES)	• Schools Committee completed review of the Asthma Management in Schools manual and is assisting in its dissemination.
Support groups	• Parent and Community Committee piloted a support group for the Vietnamese community, and were invited to conduct asthma education and support at a school.
Curriculum development	• Education, Outreach and Environment Committee completed a literature and policy review on Medicaid coverage of bedding covers and are completing a childcare education curriculum.
Fact sheet	• Clinical Committee designed a fact sheet for a potential Q&A page on the KCAF website.

Needs and resources assessment	• Communications Action Team mapped community assets within the AAA target area. • Examined data from a variety of sources, including prevalence data from the Behavioral Risk Factor Surveillance System (BRFSS), hospital discharge data, and asthma treatment information from clinical records.
Coalition Self-Assessment Survey	• Administered a coalition member survey to assess member's perceptions of coalition development.
Intervention plan development	• Held two planning retreats where interventions and action strategies were developed. • Developed a series of proposed interventions targeting clinics, schools, childcare, the home environment, and the community.

Appendix C: King County Asthma Forum (KCAF) Coalition Survey: Data Summary

Table 1: Sample Description

• Sample size (# of respondents)	N=35
	%
• Type of participation (can select more than one)	
◊ Part of paid job duties	57
◊ Volunteer	34
◊ Coalition paid staff	6
◊ Other	11
• Serve on a coalition committee *(% yes)*	80
• Perspective (can select more than one)	
◊ Health provider	46
◊ Public health department	29
◊ Community residents and organizations	29
◊ Other health/service agency	23
◊ Research/academic	23
◊ Person with asthma	17
◊ School	11
◊ Other	11
◊ Government (Local or State)	9
• Race/ethnicity (can select more than one)	
◊ African American	11
◊ White/Caucasian	83
◊ Hispanic/Latino	6
◊ Chinese	3
◊ Other	3
• Gender	
◊ Female	71
◊ Male	29
• Length of participation in HP *(% more than 6 months)*	77
• Number of coalition meetings attended in last 6 months *(% more than 6 meetings)*	34
• Hours per month, on average, spent in coalition meetings *(% 8 or more hours)*	31
• Reason for missed meetings *(can select more than one)*	
◊ Did not miss meetings	9
◊ Meeting places inconvenient	11
◊ Meeting times inconvenient/time conflict	74
◊ Not notified of meetings	0
◊ Meetings not a priority	14
◊ Other	11
• Hours per month, on average, spent on coalition work outside of meetings *(% 3 or more hours)*	43

Table 2: Respondent Satisfaction

	%
A. Planning and Implementation	
• Satisfaction with: (% somewhat or very satisfied: rating of 4 or 5 on 1-5 scale)	
◊ Clarity of vision for where the coalition should be going	44
◊ Planning process used to prepare the coalition's objectives	59
◊ Follow-though on coalition activities	61
◊ Processes used to assess the community's needs	56
◊ Training and technical assistance provided by staff	35
◊ Fairness of decision-making process	56
B. Leadership	
• Satisfaction with: (% somewhat or very satisfied: rating of 4 or 5 on 1-5 scale)	
◊ Sensitivity to cultural issues	77
◊ Opportunities for coalition members to take leadership roles	76
◊ Willingness of members to take leadership roles	53
◊ Strength and competence of staff	72
C. Participation in the Coalition	
• Satisfaction with: (% somewhat or very satisfied: rating of 4 or 5 on 1-5 scale)	
◊ Participation of influential people from key sectors of the community	39
◊ Participation of community residents and community based organizations	13
◊ Level of influence community residents and CBOs have within the coalition	19
◊ Diversity of coalition membership	36
◊ Trust shared by coalition members	63
◊ How welcoming the coalition is to new members	72
◊ Efforts to promote collaborative action	69
◊ Degree to which members are involved in making decisions	68
◊ Giving the community help in meeting the community's needs	43
D. Communication	
• Satisfaction with: (% somewhat or very satisfied: rating of 4 or 5 on 1-5 scale)	
◊ Use of the media to promote awareness of the coalition's goals, actions	7
◊ Communication between the coalition and the broader community	10
◊ Communication/networking among members of the coalition	69
◊ Extent to which members are listened to and heard by staff and leadership	64
◊ The coalition's ability to resolve conflicts that arise	52
◊ How clear and easy it is to understand the decision-making process	52
E. Progress and Outcome	
• Satisfaction with: (% somewhat or very satisfied: rating of 4 or 5 on 1-5 scale)	
◊ Progress in meeting the coalition's objectives	61
◊ Success in generating resources for the coalition	53
◊ Capacity of the coalition and its members to advocate effectively	39
◊ Coalition's contribution to improving health and human services	21
◊ Fairness with which funds and opportunities are distributed	50
◊ Degree to which members put aside their individual interests for the shared interests of the coalition	52
◊ Capacity of members to give support to each other	65
◊ Benefits to members of participating in the coalition	59